

Care Notebook



Please accept this copy of the FVND Care Notebook.

You may copy the pages for your use.

Please direct any comments, suggestions or questions to:

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Family Voices of North Dakota

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FVND Care Notebook: A Quick Guide

What is a Care Notebook?

A Care Notebook is an organizing tool for families who have children with special health care needs or disabilities. Use a Care Notebook to keep track of important information about your child's health care. This Care Notebook has been designed for families living in North Dakota.

How can a Care Notebook help me?

In caring for your child with special health needs and/or disabilities, you may get information and paperwork from many sources. A Care Notebook helps you organize the most important information in a central place. A Care Notebook makes it easier for you to find and share key information with others who are part of your child's care team.

Use your Care Notebook to:

- Track changes in your child's medicines or treatments
- List telephone numbers for health care providers and community organizations
- Prepare for appointments
- File information about your child's health history
- Share new information with your child's primary doctor, public health or school nurse, daycare staff, and others caring for your child



What are some helpful hints for using my child's

Care Notebook?

- □ Store the Care Notebook where it is easy to find. This helps you and anyone who needs information when you are not there.
- Add new information to the Care Notebook whenever your child's treatment changes.
- Consider taking the Care Notebook with you to appointments and hospital visits so that information you need will be easy to find.

Setting up Your Care Notebook



Follow these steps to set up your child's notebook:

Step 1: Gather information you already have.

Gather up any health information about your child you already have. This may include reports from recent doctor's visits, recent summary of a hospital stay, this year's school plan, test results, or informational pamphlets.

Step 2: Look through the pages of the Care Notebook.

- Which of these pages could help you keep track of information about your child's health or care?
- Choose the pages you like. Print copies of any that you think you will use. The Care Notebook pages are available from the Internet at www.geocities.com/ndfv/ Go to Resources Page and choose the "Care Notebook."

Step 3: Decide which information about your child is most important to keep in the Care Notebook.

- What information do you look up often?
- What information do people caring for your child need?
- Consider storing other information in a file drawer or box where you can find it if needed.

Step 4: Put the Care Notebook together.

- □ Everyone has a different way of organizing information. The only important thing is to make it easy for <u>you</u> to find again. Here are some suggestions for supplies used to create a Care Notebook:
- □ 3-ring notebook or large accordion envelope. Hold papers securely.
- □ Tabbed dividers. Create your own information sections.
- Pocket dividers. Store reports.
- Plastic pages. Store business cards and photographs.



FVND Care Notebook List of Pages

Pages to Keep Track of Appointments and Care

- Appointment Log
- Diet Tracking Form
- # Equipment
- Supplies
- Crowth Tracking Form
 - Crowth Charts
- ☆ Hospital Stay Tracking Form
- ☼ Information Needed by Emergency Care Providers
- ☆ Lab Work/Tests/Procedures
- Medical Bill Tracking Form
- Medical Surgical Highlights
- Medications
- Notes

Pages to Create a Care Summary: Abilities and Special Care Needs

- Activities of Daily Living
- Care Schedule
- 🌣 Child's Page
- Communication
- Coping/Stress Tolerance
- ☆ Mobility
- Nutrition
- Respiratory
- Rest/Sleep
- ☆ Social/Play
- ☆ Transitions

Pages to Create a Care Team Resource List

Community Health Care/Service Providers:

- Medical / Dental
- Public Health
- Home Care
- ☆ Therapists
- Early Intervention Services
- ☆ School
- Child Care
- Respite Care
- Pharmacy
- Special Transportation
- Recreation Opportunities
- Family Information
- Family Support Resources
- ☆ Funding Sources

Note: You may use all or just a part of these pages. Not all of the pages may apply to your family situation. For example, your child may be over age 3, and therefore not involved in Early Intervention.

Organize your pages any way that works for you. (See "Setting up Your Care Notebook.")

Use dividers or tabs to help you organize your notebook. Sheet protectors, plastic pages and folders will also be helpful in organizing material.

Appointment Log

Steps to a satisfactory medical appointment:

- Write down your problems/questions before you go.
- 2. Number the problems in questions. Make the number one the most important.
- 3. Show the provider your list. Write down any answers to your questions.
- 4. Talk to the provider about options for handling your problems/questions.

DATE	PROVI DER	QUESTIONS / PROBLEMS TO BE DISCUSSED	REASON SEEN / CARE PROVIDED	NEXT APPOI NTMENT

FVND CARE NOTEBOOK Page 7 of 48

Diet Tracking Form

	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
Tube Feeding							
Breakfast							
Lunch							
Dinner							
Snacks							
Notes							

Equipment

☼ Medical Equipment	Supplier (DME Sup	pplier):	
Contact Person:			
Phone:	 Fax:	E-Mail:	
Address:			
Notes (delivery schedule	e, order schedule, et	C.):	
∴ Name of Equipmen	t:		
Date Obtained:		Service Schedule:	
Contact Person:		Phone:	
☆ Name of Equipmen	t:		
Description (brand name	e, size, etc.):		<u></u>
Date Obtained:		Service Schedule:	
Contact Person:		Phone:	
☆ Name of Equipmen	t:		
Description (brand name	e, size, etc.):		
Date Obtained:		Service Schedule:	
Contact Person:		Phone:	

Supplies

Dhana	Fax:	F Mail:	
Contact Person:	I ax	L-iviaii.	
Phone:	Fax:	 E-Mail:	
Address:			
Notes (delivery sch	edule, order schedule, etc.):		
ITEM	DESCRIPTION	QUANTITY	NOTES

Growth Tracking Form

DATE	HEIGHT	WEIGHT	HEAD CIRCUMFERENCE	CHECKED BY

Hospital Stay Tracking Form

DATE	HOSPITAL	REASON	NOTES

FVND CARE NOTEBOOK Page 12 of 48

Emergency Preparedness for Children with Special Health Care Needs Instructions for Parents

Dear Parent:

Children with special health care needs have very unique medical histories and require very special medical treatment. If an emergency physician does not have access to this important information, these children are in danger of delayed treatment, unnecessary tests, and even serious errors. It is extremely important, then, that parents and physicians work together to give emergency physicians access to the special information they need to properly care for children with very special health care needs.

To address this problem, the American Academy of Pediatrics and the American College of Emergency Physicians have developed the Emergency Information Form. This simple form is used to record health information for children with special health care needs and should kept in multiple locations for easy access by physicians and emergency medical personnel.

To complete this important form, follow these easy instructions:

- 1. GET THE FORM: Get the Emergency Information Form from the child's primary care physician, specialist, or the local emergency room.
- 2. FILL IT OUT: Begin filling out the form to the best of your ability. Take the form to the child's primary care physician or specialist and ask them to finish filling out the form.
- 3. KEEP IT: Keep 1 copy of the form in each of the following places:
 - a. DOCTORS: On file with each of the child's physicians, including specialists.
 - b. ER: On file with the local emergency rooms where the child is most likely to be treated in the case of an emergency.
 - c. HOME: At the child's home in a place where it can be easily found, such as the refrigerator.
 - d. VEHICLES: In each parent's vehicle (i.e., glove compartment).
 - e. WORK: At each parent's workplace.
 - f. PURSE/WALLET: In each parent's purse or wallet.
 - g. SCHOOL: On file with the child's school, such as in the school nurse's office.
 - h. **CHILD'S BELONGINGS:** With the child's belongings when traveling.
 - EMERGENCY CONTACT PERSON: At the home of the emergency contact person listed on the form
- 4. REGISTER: Consider registering the child, if he or she is not already registered, with Medic Alert®. Send Medic Alert® a copy of the form so that they can keep it stored in their central database, which is easily accessible by emergency medical personnel.
- 5. UPDATE: It is extremely important that you update the form every 2-3 years, and after any of the following events:
 - a. Important changes in the child's condition.
 - b. The performance of any major procedure.
 - c. Important changes in the treatment plan.
 - d. Changes in physicians.

Now, if your child ever has an emergency, the emergency medical personnel will have easy access to your child's very unique medical history, allowing them to provide your child with the best medical care available.

Thank you for your cooperation!

Very truly yours, American Academy of Pediatrics American College of Emergency Physicians Emergency Medical Services for Children

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Emergency Information Form for Children With Special Needs







Date form completed By Whom

Revised

Initials

Revised

Initials

Name:	Birth date: Nickname:
Home Address:	Home/Work Phone:
Parent/Guardian:	Emergency Contact Names & Relationship:
	zms. gs.rsy contact rames a realisment.
Signature/Consent*:	
Primary Language:	Phone Number(s):
Physicians:	
Primary care physician:	Emergency Phone:
	Fax:
Current Specialty physician:	Emergency Phone:
Specialty:	Fax:
Current Specialty physician:	Emergency Phone:
Specialty:	Fax:
Anticipated Primary ED:	Pharmacy:
Anticipated Tertiary Care Center:	
Diagnoses/Past Procedures/Physical Exam:	
1.	Baseline physical findings:
2.	-
3.	Possiling vital cigno.
	Baseline vital signs:
4.	
Synopsis:	
	Baseline neurological status:

*Consent for release of this form to health care providers

Diagnoses/Past Procedures/Ph	nysical Exam continued:	Significant baseline	ancillary findings	(lah v rav EC)C):	
Medications:		Significant baseline	ancinary miurigs	(Iab, X-Iay, LC	,G).	
1.		_				
2.						
3.						
		2 " " "	/A			
4.		Prostheses/Appliances/Advanced Technology Devices:				
5.						
6.						
U.						
Management Data:						
	s/Foods to be avoided	and why				
Auergies: Medication	s/r voas to ve avotaea	and why:				
1.						
2						
2.						
3.						
Procedures i	to be avoided	and why:				
1.						
2.						
3.						
Immunizations (mm/yy)						
Dates		Dates				
DPT		Hep B				
OPV		Varicella				
MMR HIB		TB status Other				
Antibiotic prophylaxis:	Indication:	Other	Medication	and doco:		
Antibiotic propriyiaxis.	Indication:		ivieuication	and dose.		
Common Presenting Problems	s/Findings With Specific Sugge	ested Managements				
Problem	Suggested Diagnostic S	Studies	Treatment	Consideration	IS	
Comments on child, family, or other s	pecific medical issues:					
Physician/Provider Signature:		Print N	lame:			
		1.111(1				

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Lab Work / Tests / Procedures

DATE	TEST	RESULT	COMMENTS

Medical Bill Communication Log

Inf	Information About the Bill		Information About Who You Talk To				NOTES		
Account #	Provider	Date of Service	What bill is for:	Date of Contact	Time	Name	Title (like Account Representative)	Credentials (RN, Dr., none)	

FVND CARE NOTEBOOK Page 17 of 48

Medical / Surgical Highlights

DATE	PROCEDURE	RESULT	COMMENTS

Medications

Allergies:			
Pharmacy:			
Address:	Phone:		
	Fax:	E-Mail:	

DATE STARTED	DATE STOPPED	MEDICATION	WHAT IT IS FOR	DOSE/ROUTE	TIME GIVEN	PRESCRIBED BY	SIDE EFFECTS

Activities of Daily Living

Use this page to talk about your child's abilities to feed him or herself, bathe, get dressed, use the

bathroom, comb hair, brush teeth, etc. Descriequipment your child uses for these activities. getting dressed, etc.	ibe what your child can do by him or herself and any help on the control of the c			
Date:	-			

Care Schedule

TIME	CARE
Morning	
Afternoon	

Care Schedule

TIME	CARE
Evening	
Night	

Child's Page

Photo of Me!!!

My nickname is:
My pet is a: My pet's name is :
My "favorites"
Toys:
Animal:
Games:
Hobbies:
Songs:
T.V. Shows:
Other:
My favorite foods are:
My least favorite foods are:
My friends' names are:
Nhen I am happy I:
When I am sad I:
When I feel pain I:
Things I need help with (like washing, dressing or brushing teeth):
Things I can do for myself (but thanks for asking!):
f you need to know something else, ask me or ask:
who can be reached by calling: ()

Child's Page

Use this page for your child's words and thoughts about his or her life now as well as later.

Date:	

Communication

Use this page to talk about your child's ability to communicate and to understand others. Describe how your child communicates. Include sign language words, gestures, or any equipment or help your child uses to communicate or understand others. Include any special words your family and child use to describe things.

Date:	_	

Coping / Stress Tolerance

Use this page to talk about how your child copes with stress. Stressful events might include new people or situations, a hospital stay, or procedures such as having blood drawn. Describe what things upset your child and what your child does when upset or when he or she has "had enough." Describe your child's way of asking for help and things to do or say to comfort your child.

Date:	_	



Use this page to talk about your child's ability to get around. Describe how your child gets around. Include what your child can do by him or herself and any help or equipment your child uses to get around. Describe any activity limits and any special routines your child has for transfers, pressure releases, positioning, etc. Date: _____

Nutrition

Use this page to talk about your child's nutritional needs. Describe foods and any nutritional formulas your child takes, any food allergies or restrictions, and any special feeding techniques, precautions, or equipment used for feedings. Describe any special mealtime routines your family and child have.

Date:	-	

Respiratory

Use this page to talk about your child's respiratory care needs. Describe the care or treatments your child needs and any special techniques or precautions you use when giving care. Include any special routines your child has for respiratory care.

Date:	_	

Rest / Sleep

Use this page to talk ab Describe your child's be	out your child's ability to get to dtime routine and any security	o sleep and to sleep through the ni y or comfort objects your child use	ght. S.
Date:			

Social / Play

Use this page to talk about your child's ability to get along with others. Describe how your child shows affection, shares feelings, or plays with other children. Describe what works best to help your child get along or cooperate with others. Describe your child's favorite things to do. Include any special family activities or customs that are important.

Date:		

Transitions - Looking Ahead

Your child and family will experience many transitions, small and large, over time. Three predictable transitions occur for most children: reaching school age, approaching adolescence, and moving from adolescence into adulthood. Many children do not experience these transitions in the way most children experience them. Other transitions may involve moving into new programs, working with new agencies and care providers, or making new friends. Transitions involve changes: adding new expectations, responsibilities, or resources, and letting go.

Looking at transitions may be hard, depending on your circumstances. You may have limited time just to do what needs to get done today. You may find it helpful, though, to jot down a few ideas about your child's and family's future. You might start by thinking about your child's and family's strengths. How can these strengths help you plan for "what's next" and for reaching long-term goals? What are your dreams and your fears about your child's and family's future?

Date:	 _	

Medical / Dental <u>Community Health Care Providers</u>

⇔ Primary / Commun Date of First Visit:	nity Care Provider:		
Office Nurse/Medical	 Δssistant·		
Phone:	Fax:	E-Mail:	
☆ Primary Children's Medical Record Numl Address:	ber:		
Phone:	Fax:		
Medical Record Num	ber:		
Phone:	Fax:		
Specialty: Office Nurse/Medical	Date of Firs	st Visit: E-Mail:	
1 Hone	T dA	L Maii	
Specialty: Office Nurse/Medical	Date of Firs Assistant:	st Visit:	
Address: Phone:	Fax:	E-Mail:	
Date of First Visit:			
Phone:	Fax:	E-Mail:	
⇔ Orthodontist: Date of First Visit:			
Phone:	Fax:	E-Mail:	
		viders on the next page.	

Providers (Continued)

Many specialty physicians may treat your child. You may keep track of some them here:

	ty Care Provider:	
Specialty:	Date of First Visit:	
Office Nurse/Medical A	ssistant:	
Address:		
Phone:	Fax:	E-Mail:
	ty Care Provider:	
Specialty:	Date of First Visit: _	
Office Nurse/Medical A	ssistant:	
Address:		
Phone:	Fax:	E-Mail:
Community Special	y Care Provider:	
Specialty:	Date of First Visit: _	
Office Nurse/Medical A	ssistant:	
Address:	<u>-</u>	
Phone:	Fax:	E-Mail:
☆ Community Specials	ty Care Provider:	
Office Nurse/Medical A	esistant	
Address.	3313turit	
Phone:	Fax:	E-Mail:
☆ Community Specials ☆ Community Spec	ty Care Provider:	
Specialty:	Date of First Visit:	
Address:		
Phone:	Fax:	E-Mail:
X Community Special	tu Cara Dravidari	
Office Nurse/Medical A	Date of First Visit: _	
Address:	Fave	E Mail:
FIIUIIE	Fax:	E-IVIAII

Home Care Providers

☆ Home Care Agency			
Phone:	Fax:	E-Mail:	
	:		
Start Date:			
Case Manager:			
Other Contacts (schedu	ıler, billing, etc.):		
Phone:	Fax:	E-Mail:	
	:		
Start Date:			
Case Manager:			
Primary Care Nurse:			
		E-Mail:	

Therapists

☆ Occupational Them ## Occupation	nerapist (OT):		
Address:			
Phone:	Fax:	E-Mail:	
☆ Physical Therap	oist (PT):		
Start Date:			
Agency / Hospital / (Clinic:		
Address:			
Phone:	Fax:	E-Mail:	
☆ Speech-Langua	ge Pathologist:		
Start Date:			
Agency / Hospital / (Olinic:		
Address:			
Phone:	Fax:	E-Mail:	

Early Intervention

The Early Intervention Program Early intervention means early assistance. Here in North Dakota, a special kind of partnership between parents and professionals gives every child the best possible start in life. The Department of Human Services' Infant Development/Early Intervention programs are designed to help your child and your family gets the supports you want and need. This program is designed to identify children at risk in the earliest stages, when the right help can make all the difference. This program is to support eligible children and families in enhancing a child's potential growth and development from birth to age three.

🜣 My Early Interventi	on Program agency: _		
Date contacted:			
-			
Phone:	Fax:	E-Mail:	
Schedule:			

If you live in this Region:	Contact this Agency:	At this Telephone Number:
Williston	Northwest Human Service Center	701-774-4600
Minot	Minot State University	701-858-3054
Devils Lake	Lake Region Kids	701-662-6324
Grand Forks	Northeast Human Service Center	701-795-3000
Fargo	Southeast Human Service Center	701-298-4500
Jamestown	South Central Human Service Center	701-253-6300
Bismarck	Bismarck Early Childhood Education Program	701-221-3490
Dickinson	K.I.D.S.	701-483-4394

School Contacts

⇔ School District: Address:			
Phone:	Fax:		
Special Education Coordinate Address:	Dr:		
Phone:	Fax:	E-Mail:	
504 Accommodation Plan Co			
Address:Phone:	Fax:	E-Mail:	
District Nurse assigned to yo Address:			
Phone:	Fax:		
⇔ School / Preschool: Address: Phone:			
Principal / Administrator: Phone:	Fax:	E-Mail:	
Classroom Teacher: Phone:	Fax:	E-Mail:	
Resource Instructor:Phone:	Fax:	E-Mail:	
Aide / Assistant / Intervener:			(Some parents store IEP and 504 plan
Phone:	Fax:	 E-Mail:	information in sheet protectors following this section.)
Special Education Director / 1	Feacher(s):		,
Phone:	Fax:	E-Mail:	
Therapist(s):			
Phone:	_ Fax:	E-Mail:	

ner Contacts: _	 	 	

Child Care

☆ Child Care Provider:			
Start Date:			
Address:			
	Fax:	E-Mail:	
Important Information:			
☆ Child Care Provider: _			
Start Date:			
Contact Person:			
Address:			
Phone:		E-Mail:	
Important Information:			
☆ Child Caro Drovidor:			
Start Date:			
Address:			
Phone:	Fax:	E-Mail:	
Important Information:			

Respite Care

☆ Respite Care Provider	· ·		
Start Date:			
Address:			
Phone:	Fax:	E-Mail:	
☆ Respite Care Provider	:		
Start Date:			
Contact Person:			
Agency:			
Phone:	Fax:	E-Mail:	
☆ Respite Care Provider	:		
Start Date:			
Address:			
Phone:	Fax:	E-Mail:	
If applicable:			
Fiscal Agent:		Contact:	
Phone:	Fax:	E-Mail:	

Pharmacy

Medical professionals suggest that, if possible, you use one pharmacy for all your prescription medicine needs. In this way, your pharmacist may keep track of all medications being used and any possible problems with interactions between medications. Sometimes, however, you may need to have prescriptions filled at your neighborhood pharmacy and other times your may need to have them filled at the hospital pharmacy. Use this space to keep track of all your pharmacy providers.

Address:		
		E-Mail:
☆ Pharmacy:		
Contact Person:		
Phone:	Fax:	E-Mail:
⇔ Pharmacy:		
Contact Person:		
Address:		
Phone:	Fax:	E-Mail:
Important information	n for the pharmacist (Such a	as allergies to medication):
	· · · · · · · · · · · · · · · · · · ·	

Special Transportation

☆ Transportation (to and from medical / therapy	appointments):	
Contact person:			
Agency:			
Address:			
Phone:	Fax:	E-Mail:	
Important informati	on (such as bus route, rules re	garding pick-up, etc.):	
•	to and from medical / therapy	appointments):	
Agency:			
Phone:	Fax:	E-Mail:	
Important informati	on (such as bus route, rules re	garding pick-up, etc.):	

Recreation

A number of organizations have programs designed to give children and adults with special needs Recreation opportunities. These include local park and recreation programs. Check with your providers to find out more about recreation opportunities close to your home. Some parents include brochures and activity calendars in this section of their Family Voices of North Dakota Care Notebook.

Recreation Opportu	nity:		
Contact Person:			
Address:			
Phone:	Fax:	E-Mail:	
☆ Recreation Opportu	nity:		
Contact Person:			
Address:			
Phone:	Fax:	E-Mail:	
Schedule:			
☆ Recreation Opportu	nity:		
Contact Person:			
Address:			
Phone:	Fax:	E-Mail:	
Schedule:			
Notes:			

Family Information

☆ Child's Name:		Nickname:		
Date of Birth:	Social Secur	ity Number:		
Diagnosis:				
Blood Type:				
Legal Guardian:				
Address:		Phone:		
	Family M	1embers		
₩ Mother's Name:				
Social Security Number:Address:				
Daytime Phone:		Evening Phone		
☆ Father's Name:				
Social Security Number:				
Address:				
Daytime Phone:		Evening Phone	:	
⇔ Sibling's Name:	Age:	Name:		Age:
⇔ Sibling's Name:				
☆ Other household members:				
Other language(s):				
Interpreter Needed? Yes:			Dhan	
Preferred interpreter? Name:			Phone:	
W M	Emergency			
★ Name:				
Address:				
Daytime Phone:		Evenina Phone		

Family Support Resources

Address/Directions:			
Phone:	Fax:	E-Mail:	
Contact Person:			
Phone:	Fax:	E-Mail:	
Contact Person:			
Phone:	Fax:	E-Mail:	
Contact Person:			
Phone:	Fax:	E-Mail:	
Contact Person:	-	ilities (DSPD):	
Phone:	Fax:	E-Mail:	
⇔ Other: Contact Person: Address/Directions: _			
Phone:	Fax:	E-Mail:	
Contact Person:			
Phone:	Fax:	E-Mail:	

Insurance, Etc.

☆ Primary Insurance Compar	ny:	
Policy Number:		
Contact Person / Title:		
Address:		
Phone:	Fax:	
☆ Secondary Insurance Com	pany:	
Policy Number	puny	
Contact Person / Title:		
Address:		
Addi 033		
Phone:	Fax:	
name and ID Number on the NID Number:	oplicable – this is the company name that appears about dentification Card): orker:Fax:	
☆ Supplemental Security Income.	ome (SSI):	
Contact Person / Title:		
Address:		
	Fax:	
☆ Other:		
Policy Number:		
Contact Person / Title:		
Address:		
Phone:	Fax:	

Notes
